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## Resilience in the Face of Adversity: Stories from Adults with Fetal Alcohol Spectrum Disorders

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### Abstract

This study explored the school and life experiences of four adults diagnosed with a fetal alcohol spectrum disorder (FASD) from an urban area in western Canada. Semi-structured interviews provided insight into the lives of these adults, including their experiences with this disorder as it related to their social interactions and peer relationships in elementary school, high school, and the community. Their educational and life experiences were examined with the goal of understanding how success is achieved among these individuals. Three major themes emerged from participant interviews: (a) "I don't fit in": negative school experiences leading to anger and frustration toward diagnosis; (b) intergenerational alcoholism, child abuse, and drug addiction; and (c) healing the wounds: sources of strength, success, and helping others. Despite the hardships these participants faced, they each found sources of strength and success that have allowed them to be resilient in the face of adversity.

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### **Cover Page Footnote**

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## **Resilience in the Face of Adversity: Stories from Adults with Fetal Alcohol Spectrum Disorders**

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### **Abstract**

*This study explored the school and life experiences of four adults diagnosed with a fetal alcohol spectrum disorder (FASD) from an urban area in western Canada. Semi-structured interviews provided insight into the lives of these adults, including their experiences with this disorder as it related to their social interactions and peer relationships in elementary school, high school, and the community. Their educational and life experiences were examined with the goal of understanding how success is achieved among these individuals. Three major themes emerged from participant interviews: (a) “I don’t fit in”: negative school experiences leading to anger and frustration toward diagnosis; (b) intergenerational alcoholism, child abuse, and drug addiction; and (c) healing the wounds: sources of strength, success, and helping others. Despite the hardships these participants faced, they each found sources of strength and success that have allowed them to be resilient in the face of adversity.*

Prenatal alcohol consumption is known to adversely affect the unborn child, resulting in a range of lifelong developmental disabilities and hardships (Connor & Streissguth, 1996). These disabilities affect not only the individual, but also the family, community, and all of society (Chudley et al., 2005; Saskatchewan Learning, 2004). Fetal alcohol spectrum disorder (FASD) is an umbrella term, not a diagnostic term, that is used to collectively refer to the wide range of effects caused by the consumption of alcohol during pregnancy (Chudley et al., 2005; Ryan, Bonnett, & Gass, 2006; Saskatchewan Learning, 2004). These effects differ in each individual but often include some forms of physical, mental, behavioural, and learning disabilities that persist into adulthood and therefore have varying impacts across the lifespan (Chudley et al., 2005). Three diagnostic categories

exist within the umbrella term, each displaying its own set of associated characteristics: fetal alcohol syndrome (FAS); partial fetal alcohol syndrome (partial FAS); and alcohol-related neurodevelopmental disorder (ARND), which includes the previously used term *suspected fetal alcohol effects* (FAE) (Chudley et al., 2005; Green, 2007; Saskatchewan Learning, 2004).

Parents of children with FASD often struggle with their children's numerous behaviour problems, keeping the children involved in social activities, and collaborating with school personnel (Brown & Bednar, 2004). FASDs are the leading known cause of developmental disabilities within Canada (Public Health Agency of Canada, 2008). Direct costs associated with FASDs have been estimated at \$1.5 million per person across a lifetime (Public Health Agency of Canada, 2005) including direct health, social, and justice system costs and the indirect costs related to mortality, disability, and incarceration (Ryan et al., 2006). Although difficult to estimate accurately, it is projected that 9 out of every 1,000 babies are born with FASDs in Canada each year (Public Health Agency of Canada, 2005). Given the history of colonization and devaluation of culture in some high-risk communities such as First Nations and Inuit populations, rural areas, and isolated northern communities, the birth rates of children born with FASD may be as high as one in five (Health Canada, 2001; Public Health Agency of Canada, 2005). It is estimated that each year within Canada, more than 3,000 babies are born with FASDs, and around 300,000 more people are currently living with this disorder (Health Canada, 2006). In light of this high prevalence rate, it is important that the experiences of individuals with FASDs be expressed and understood.

The range of effects caused by prenatal alcohol exposure varies among individuals, but it is generally characterized by primary disabilities in: executive functioning, which includes planning and abstract thinking (Connor, Sampson, Bookstein, Barr, & Streissguth, 2000); cognitive capacity (Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998); memory and behaviour (Streissguth, 2007); social skills (McGee, Fryer, Bjorkquist, Mattson, & Riley, 2008); and impulse control (Connor et al., 2000; Streissguth, 2007). Individuals with FASDs also exhibit secondary disabilities, which occur after birth and are direct manifestations of primary disabilities, such as mental health problems, inappropriate sexual behaviours, disrupted school experience, and trouble with the law (Government of Canada, 2007; Saskatchewan Learning, 2004). These difficulties hinder the ability of individuals with FASDs to behave in socially acceptable ways and, therefore, discourage the successful formation of positive peer relationships (Kelly, Day, & Streissguth, 2000; Thomas, Kelly, Mattson, & Riley, 1998).

Much of the previously completed research concerning prenatal alcohol exposure was quantitative in nature (e.g., Bishop, Gahagan, & Lord, 2007; Frankel, Paley, Marquardt, & O'Connor, 2006; McGee, Bjorkquist, Price, Mattson, & Riley, 2009; O'Connor et al., 2006; Rasmussen & Bisanz, 2008; Schonfeld, Paley, Frankel, & O'Connor, 2006, 2008). However, many more qualitatively oriented studies have considered the perspectives and experiences of individuals who have actually been diagnosed with a FASD and of their families (e.g., Astley, Bailey, Talbot, & Clarren, 2000; Duquette & Stodel, 2005; Duquette, Stodel, Fullarton, & Hagglund, 2006; Jones, 2004; Massey, 1997; Rutman, 2013; Ryan & Ferguson, 2006). For example, Ryan and Ferguson (2006) explored the diagnostic process and the experiences of professionals and

family members associated with five Alaskan students with a FASD. Although these researchers did not interview the students with FASD directly, more than 400 hours were spent observing the students in their homes, in school or treatment facilities, and during different activities (Ryan & Ferguson, 2006). They found: (a) despite an increase in public awareness, limited services exist for children diagnosed with FASDs and for their families; (b) beginning teachers are less likely to adapt instruction for students with FASDs, while experienced teachers use differentiated instruction more readily; and (c) there is a persistent impact of challenging behaviours, but limited support provided to families (Ryan & Ferguson, 2006). Duquette et al. (2006) used a case study design to investigate the experiences of eight secondary students with FASD and why they have persisted and stayed in school. Researchers' cross-case analysis suggested their participants did not critically evaluate their relationships with others or their academic progress. Participants perceived themselves to have friends, be passing their classes, and "as a result they felt academically and socially integrated into their school" (Duquette, et al., 2006, p. 228). Participants also identified parental support as a significant part of why they were persistent and stayed in school. In a more recent study, Burnside and Fuchs (2013) considered the lived experiences of 20 youth with FASD who were transitioning, or had recently transitioned, from care in the child welfare system to adulthood. Participants' perspectives were systematically arranged around five main themes: "(a) the role that FASD plays in the lives of adolescents in care; (b) the critical need for consistent relationships; (c) developmental experiences for youth with FASD; (d) challenges in adolescence; and (e) transition planning for youth with FASD at age of majority" (Burnside & Fuchs, 2013, p. 45). Considering the theme related to the importance of relationships, participants voiced their desires to have "'real' family connections" (p. 45) sharing that the lack of a supportive relationship with their biological families has caused them a lot of emotional pain. These participants wanted "genuine relationships with people who will love them for who they are..." (p. 50). As highlighted by the findings in these studies, there is much to be learned from considering the perspectives and experiences of individuals who have been diagnosed with a FASD.

In addition, effective interventions need to be based on the educational and individual needs of those diagnosed with FASDs to reduce the costs of FASDs on Canadian society and expand educators' and helping professionals' understanding and ability to address students' needs. Educators can use various evidence-based strategies to support the learning needs of students with FASD, such as building a good relationship with the student, breaking up learning tasks into smaller steps, and ensuring the learning environment is free from clutter (Carpenter, 2011; Roberts, 2015). Studies are starting to consider specific interventions that can better support individuals diagnosed with FASD (e.g., Astley, 2014; Jirikowic, Gelo, & Astley, 2010). Jirikowic et al. (2010) summarized 12 subcategories of interventions that have been recommended to address the multifaceted needs of individuals diagnosed with FASD at a diagnostic clinic at the University of Washington, including: (a) family support-resources (i.e., advocacy and/or education, personal and/or peer support); (b) medical (i.e., vision and/or hearing evaluation, ADHD evaluation); (c) anticipatory guidance and/or prevention (i.e., reproductive health, substance abuse prevention); (d) social service and/or child welfare (i.e., caregiver resources, placement advocacy); (e) developmental therapy (i.e., referral

to a speech-language pathologist or an occupational therapist); (f) education and/or assessment (i.e., monitor a specific area of performance, referral to educational service); (g) community-based activities (i.e., special interest groups, prosocial extracurricular and/or play activities); (h) safety awareness (i.e., personal identification and/or safety); (i) mental health (i.e., individual or family counselling); (j) adult transitioning and/or future planning (i.e., financial, vocational); (k) accommodations (i.e., communication, behaviour and/or emotional regulation); and (l) developmental therapy (i.e., referral to a therapeutic social skills group). These authors commented that their data demonstrated similar areas of need, and intervention recommendations were made for children diagnosed with a variety of FASD conditions. However, there is still “limited evidence for specific interventions for children with FASD” (Peadon, Rhys-Jones, Bower, & Elliott, 2009, p. 6) when considering “pharmacological, behavioural, speech therapy, occupational therapy, physiotherapy, psychosocial and educational interventions and early intervention programs” (Peadon et al., 2009, p. 1).

The first author’s personal interest in FASDs began when a family member who was adopted revealed the long-held secret that her birth mother admitted in her birth records to having consumed alcohol while she was pregnant. When this adoption took place in the 1970s, the direct connection between prenatal alcohol consumption and the significant effects on the fetus were not completely understood. This family member then went on to have two children of her own. It was not until many years after the birth of her children that this family member admitted that she had consumed alcohol while she was pregnant with both of her children. One child was diagnosed with partial FAS and the other child with ARND. These diagnoses soon ignited an interest in learning about FASDs so the first author could help her own family have a better understanding as to why these family members who had been prenatally exposed to alcohol often displayed certain behaviours. She could also use her knowledge to educate her family about FASDs in hopes that they would educate others and stop the cycle of this disorder within their family. Therefore, the first author undertook this study as a student researcher completing the thesis requirements for her Master of Education degree under the supervision of the second author.

## **Purpose**

Numerous studies have focused on the impairments individuals with FASDs encounter and how this can lead to difficulty in school (Coles, Lynch, Kable, Johnson, & Goldstein, 2010; Olson et al., 1997; Rasmussen & Bisanz, 2008; Riley & McGee, 2005; Stuss & Knight, 2002). Researchers are also considering the school and life experiences of those with FASDs from their perspective (e.g., Burnside & Fuchs, 2013; Duquette & Stodel, 2005; Duquette et al., 2006; Massey, 1997; Rutman, 2013). Expanding the research related to the personal experiences of individuals diagnosed with FASD can only enhance educators’ and helping professionals’ (i.e., social workers, counsellors, psychologists, speech-language pathologists, etc.) understanding of, and ability to develop, appropriate programs, accommodations, and supports to help these individuals experience success in school, which can positively influence their experiences later in life. Therefore, the aim of this study was to further contribute to this body of research by seeking the perspectives of those who have been prenatally

exposed to alcohol. Identifying their direct needs in their own words may allow educators, parents, and all those who work and care for individuals with FASDs to begin to address and improve their outcomes in life. The current study focused on the experiences of four adults who were diagnosed with a specific FASD. The purpose of the study was to describe and understand their experiences, with the hopes of coming to a greater understanding of how success is achieved among these individuals. The research questions that guided this inquiry were: (a) What are the school and life experiences of those diagnosed with FASDs? and (b) What has allowed these individuals to achieve success in school and life situations?

## **Methodology**

A basic qualitative approach (Merriam, 2002) was used to gain an in-depth understanding of how the participants' school experiences have influenced their lives, while also exploring themes of resilience and success. Although all qualitative research is interested in how people understand their lives and worlds, a basic qualitative inquiry's most important goal is to uncover and interpret these meanings.

## **Participant Selection and Recruitment**

Upon approval of a university ethics board, purposeful sampling was used to recruit four adults diagnosed with a FASD to participate in the current study. Criteria used to determine participant eligibility included: (a) age: all participants were between 18–30 years of age; (b) diagnosis: all participants were diagnosed (as reported by the individual) with FAS, partial FAS, or ARND (which includes FAE); (c) ability and willingness: all participants were willing and able to share their school and life experiences of being diagnosed with a FASD; (d) well-being: all participants were not in any immediate crisis, such as currently experiencing emotional, physical, or psychological distress; and finally (e) history: all participants currently were, or previously had been, a student in school.

Participants were recruited through a Call to Participate notice posted in community locations in and around an urban area in western Canada. Before the interview process began, each participant was screened for eligibility through a telephone conversation with the student researcher. This phone conversation was used to demonstrate potential participants' ability to understand, formulate their thoughts, and respond orally in a clear, concise manner to posed questions (see Appendix A). This was an important process to ensure participants understood what was being asked of them and to protect their interests. The student researcher spoke with five potential participants who contacted her to express their interest in participating in the study. She judged all five individuals to be effective communicators, since each person did not experience any difficulties understanding and responding to each of the posed questions. One potential participant was not included in the study because a suitable meeting time and place could not be organized for the interview due to conflicting schedules. After the screening process, if participants agreed to take part in the study, a mutually agreed upon time and place for the first interview was established.

## **Data Generation**

Each individual met with the student researcher for one main interview. Interviews were conducted in a public location that offered privacy and was convenient for both the participants and the student researcher. These locations included private meeting rooms in university and/or public libraries during library hours, or at the offices of the community organizations from which participants were recruited. Informed consent was obtained through a written consent form that was introduced, reviewed, and signed at the beginning of the first interview. The initial interviews were digitally recorded and preceded for approximately 45–150 minutes. In order for the participants to feel as comfortable as possible, the student researcher began each interview by sharing her personal story about who she was and what interested her in studying this topic. This often led the participants to ask questions about the student researcher's family. One participant even informed her that he was now more comfortable sharing his story because he knew she would not think he was "slow or stupid." After each interview, the student researcher transcribed the information. Each interview consisted of open-ended questions, such as: "How did you find making friends in school?", "What are some things that have helped you be successful in school?", and "What has your experience of being diagnosed with (FAS, partial FAS, or ARND) in school been like?" (see Appendix B). The student researcher first administered and reviewed the interview questions with one of her family members who has a FASD diagnosis to ensure the questions were concrete, understandable, and would not lead participants' responses.

The second follow-up meeting lasted approximately 45–60 minutes and involved reading over the summarized transcript from the previous interview with the participant in order to increase the study's credibility. Any information that could potentially identify participants was altered or deleted, and each participant was given a pseudonym. The student researcher went through the transcript with the participant, answered any questions they had, and assured them they could modify the transcript in any way. Only two of the participants sat down with the student researcher and made significant changes to the document. One participant opted not to review his/her transcript, and one participant chose to review the transcript through email.

## **Data Analysis**

The data analysis process involves "consolidating, reducing, and interpreting what people have said and what the researcher has seen and read" (Merriam, 2002, p. 176). Data analysis began by identifying segments within the data that answered the research question; upon reading the transcript for the first time the student researcher used open coding by making notes, comments, and observations in the margins of the transcript (Merriam, 2002). After going through the entire transcript in this manner, the notes, comments, and observations became the codes that were then transferred onto cue cards. The cue cards were reviewed and those that fit together were put in the same group. Once each card had a group, the cards were examined for a common theme. The themes were then derived from these groupings and the theme names formed. This analysis extends beyond what any individual may see in his or her own experience (Janssen, Henderson, & Vedam, 2009). This is because the individual has a deep understanding of his or her own



experience, while the researcher has access to the insights of many participants (Janssen et al., 2009). The student researcher focused on the unique experiences of each participant and on the commonalities and differences among them. This in turn led to a greater understanding of the school experiences of these individuals with FASDs and how these experiences influenced their lives. The present study also incorporated resiliency theory (Luthar, Cicchetti, & Becker, 2000; Masten, 2001) as a framework for understanding and analyzing the data. Resilience can be defined as the ability to positively adapt despite experiencing significant adversity (Luthar, Cicchetti, & Becker, 2000; Masten, 2001). Resilience has also been described as a set of adaptive cognitive, behavioural, and emotional responses to acute or chronic adversities which can be unusual or common. These adaptive responses can be learned and are within the grasp of everyone; resilience is not a rare quality only given to select individuals. While many factors affect the development of resilience, the attitude you adopt to deal with adversity is at the heart of resilience (Neenan, 2009).

## **Results**

Participants' quotations were edited to protect confidentiality and increase readability. Specific names were altered or eliminated and repetitive and unnecessary words, such as *yeah*, *you know*, *like*, were deleted. Three major themes were identified in the stories of the participants: (a) "I don't fit in": negative school experiences leading to anger and frustration toward diagnosis; (b) intergenerational alcoholism, child abuse, and drug addiction; and (c) healing the wounds: sources of strength, success, and helping others.

## **Participants**

The participants in this study were four adults from an urban area in western Canada; two of Indigenous descent and two of non-Indigenous descent. Participants ranged in age from 19 to 30 years and included two males and two females assigned the pseudonyms Derek, Madison, Teresa, and Brandon.

The first participant interviewed was Derek. At the time of the interview he had recently celebrated his 30th birthday. In his youth, Derek was diagnosed with FAE and ADHD. He experienced many struggles throughout his life, especially in school, that were related to his diagnoses of hyperactivity, distractibility, and communication difficulties. However, many of the struggles that Derek faced in life also had to do with his home environment. He grew up in a physically and emotionally abusive home where alcohol was being abused by both of his parents. During his teenage years he also began abusing drugs and alcohol himself. Despite these hardships, Derek graduated high school, went on to become a hockey coach, and was 154 days sober at the time of the interview.

The next participant interviewed was Madison, who was 20 years old at the time. Madison was diagnosed with partial FAS when she was a young child. She also grew up in a home where her mother abused alcohol. When Madison was around 10 years of age, she and her siblings were put into foster care because her mother was not able to properly care for them. Once her mother began living a sober life, she regained custody of her children and raised them until they were grown. Madison credited her mother for

providing her with the strength and courage to speak out and stand up for herself when she needed assistance or did not understand something being taught in class. Madison graduated high school and at the time of the interview had plans to apply to a university social work program in the near future.

Teresa, who was 30 years of age, was the third interview completed by the student researcher. She revealed that although she was diagnosed with FAE when she was a child, she did not find out about her diagnosis until she was an adult while looking through her social work file. She was adopted as a young child and suffered both physical and emotional abuse at the hand of her adoptive mother. During her school years, she always felt like she did not fit in and had a hard time making friends. Drama class proved to be the place where Teresa felt most comfortable. Here she was able channel the pain she was feeling inside into her drama performances, which helped her cope with some of her emotions. Later in life Teresa became addicted to drugs and alcohol. At her lowest point she was injecting herself with drugs and engaging in prostitution. One day Teresa realized that she was meant to do more with her life and began the process of getting clean and sober. Teresa maintained her sobriety and was even using her story to inspire and help other addicts who are in the same place she was years ago. At the time of the interview, Teresa had recently been accepted into a post-secondary institution where she was planning to take a community addictions program.

The last and final participant interviewed was Brandon. Brandon was finishing up his final year of high school at the time of the interview and was 19 years of age. Brandon was adopted into a middle-class home around the age of 1. He grew up with two siblings and very supportive parents. Brandon had numerous difficulties with school and was on an Individualized Education Plan (IEP) for most of his high school years. He also experienced difficulty making friends and often got into trouble at school due to his disruptive behaviour. However, once he began playing sports, he made many new friends and began enjoying school. At the time of the interview, Brandon had recently graduated Grade 12 and was working at a local community centre.

Participants were recruited through their contact with community organizations designed to provide services for individuals affected by FASDs and for their families. Thus, the participants in the current study have accessed these service to improve their quality of life. Given this factor, these participants demonstrated aspects of resiliency.

### **Theme 1: “I Don’t Fit In”: Negative School Experiences Leading to Anger and Frustration Toward Diagnosis**

Derek shared, “At times I was bullied in school, and I didn’t really have a lot of friends. No one really wanted to be friends with anyone who was slow.” Derek, Madison, Teresa, and Brandon all experienced difficulty making friends, were bullied by their peers, and got into trouble at school. Although each participant had slightly different experiences, common to all four individuals was a sense that they did not quite fit in. As Derek explained, he was a loner who did not have many friends and had to avoid fighting at school when he was being bullied: “I was also a follower, I always listened to what others told me to do. People would tell me to do something and I would do it because I

wanted to have friends.” Madison revealed she felt like an outcast and was also bullied at school: “Being bullied in school was also hard for me, and it made my days at school worse. Some days I didn’t even want to go to school ‘cause I was worrying about what they would say next.” Teresa described not fitting in at school and acting out because of the abuse occurring at home:

In Grade 4 I was the class clown ... I really acted out a lot ‘cause there was a lot of abuse going on at home and stuff so ... I was always on the outside looking in. The only way I did get attention was by being bad or out of control. Well, not so much out of control but just kind of wild, trying to be funny, trying to be different. Because I always felt like I didn’t fit in and then I was like, okay then, I’m going to be different.

Brandon also shared it was hard for him to make friends in school: “Some people when they come to school they are mean to me.... I am shy sometimes, too, so that is hard. I never really had any friends until I got into high school ‘cause I started to play sports.” As previously stated, common to all stories is a sense that they did not belong and were outsiders at school. Another commonality that Derek, Madison, and Brandon discussed was getting into trouble at school. Derek recalled his experience with teachers at his school: “Well, I was the class clown, so they [the teachers] didn’t like me much. I was hyperactive, like I said before, so I was sent outside to the hallway all the time.” Madison explained how her dislike of a teacher caused her to get into trouble: “He would try teaching one thing and I would disagree and we would get into arguments ... It would get so personal, and that’s what would get me into trouble.”

Another common experience that Teresa, Madison, Derek, and Brandon all discussed was difficulty with school subjects, especially mathematics. Teresa found her Grade 10 math class to be extremely frustrating when she could not do the work on her own:

The teacher would do the question on the board, and I got it and it would make sense. Then I would sit down in my desk and try to do my work, and I couldn’t do it! I didn’t get it. She would come over to my desk and do the question step by step with me, and it made sense. She would get up and leave. Then the next question I would try to do on my own and I couldn’t! ... I wanted to get it and I wanted to learn.

Madison also discussed how her difficulty with school was related to her inability to pay attention when she did not understand the material being taught: “I didn’t get it so that’s what made me not want to listen. Math was really hard for me. It’s still really hard, and I still don’t like it. Honestly, I really don’t know how I passed!” Derek shared how he attended special classes in elementary school to address his difficulties with school subjects such as math and his communication skills: “They would tell me to slow down when I was talking: ‘It’s not a race,’ they would say. To this day I still find it hard to comprehend what other people say and to communicate with people.” Having these negative experiences in school, which were commonly related to their diagnosis, often led the participants to become angry and frustrated with their diagnosis. Brandon discussed how he sometimes feels angry about having been diagnosed with a FASD: “The way I am and the stuff I do, sometimes it gets me angry. I can’t do most things that

other people can, and it makes me angry. It's really hard, like in school and stuff." Derek explained his frustrations:

I didn't ask to be brought into the world this way ... having FAS. I was born this way, and I can't do nothing about it but live my life. But I just want other people to know that it is hard for some people to accept that I have a problem. But that's just the way it is, I can't change it.

Teresa discussed the anger that was inside of her:

Like I just had this wall up, don't talk to me, don't look at me, because I am such a loser, and why would anyone want to talk or look at me? So I put out this f-you image, don't look at me, don't talk to me, I don't exist. You know I just had all this anger inside of me because I had some self-esteem issues and also because I didn't fit in.

Derek, Madison, Teresa, and Brandon each described the difficulties that they had at school. Being bullied, feeling like they did not fit in, and having difficulty making friends were all common themes to the participants. Another commonality among all four of the participants was getting into trouble at school. The trouble that the participants got into at school was often because they did not understand what was being taught in the classroom. These difficulties with school often caused the participants to become angry and frustrated with their diagnosis. The following theme relates to family alcoholism, physical abuse, and the participants own experiences with drug and alcohol addiction.

## **Theme 2: Intergenerational Alcoholism, Child Abuse, and Drug Addiction**

Derek shared, "Love for me came in a bottle. A gallon of wine. If there was no more alcohol I would get hit. That's how I grew up to be numb." Derek, Madison, and Teresa all spoke candidly about a family history of alcoholism. Alcoholism was not a secret, and from an early age the participants knew what alcohol was and how it affected the people who were abusing it. Derek talked about his experience growing up in a home where his parents drank and were physically abusive: "I was abused when I was a kid.... When they [his parents] were drinking everything was fine ... well, not fine, but better. When the money ran out so did the alcohol, and that's when I had to watch out." Teresa discussed wanting to be at school rather than at home, to escape the abuse by her adoptive mother: "I hated Fridays, hated them, and I loved Mondays ... school was my safe haven. School was actually where I got to be myself without getting hurt or punished or ridiculed." Although Madison did not experience abuse growing up, she spoke about family alcoholism:

She [her mother] would always tell me about my family and how they all drink and how they are all dying one by one, and I did not want to grow up like that. My mom quit drinking for us [her children].... But I was just so used to people always drinking, and I just thought that that was the way it was supposed to be. And she was like, "NO!" She taught us about family traditions and how to live a healthy life. So I am really happy that I learned these things from her. She always says, "What doesn't kill you makes you stronger," and I like that message.

Teresa talked about the alcoholism and abuse in her family, sharing that her mother died from alcoholism and her father, who is an alcoholic, is also dying: "I didn't get to know her [my mother] very well, we got into an argument over my older sister. There was some

abuse from my sister to her children, and I phoned social services on my sister, which was really hard.”

These early experiences with alcoholism within their families, and in some cases physical and emotional abuse, shaped how the participants viewed alcohol and other drugs. Derek, Madison, and Teresa all experimented with drinking as early as 13–14 years of age. Derek and Teresa also experimented with drugs and unfortunately quickly became addicted. Here, Derek spoke about how drugs and alcohol shaped his upbringing:

You know I’ve done some stupid things in the past ... I don’t need it and I don’t want it, but if I have money, I am going to buy it. So I want to go to treatment and get help ... It’s difficult to talk about it, but at the same time if it’s going to help someone else out, then I’m all for it.

Madison talked about how she lost a lot of friends in high school when she quit drinking and would not do drugs: “I would go out drinking with them, but I never touched drugs. Then one day I even stopped that because I would see my aunties and I didn’t want to be like them.” Teresa explained how she started drinking and experimenting with drugs in Grades 9 and 10 and having sex with different partners:

In Grade 10, I was in the pot-head crowd, and they would ask me almost every day at lunch time if I wanted to go and get high.... I stopped drinking by the time I hit 11th grade because it wasn’t like I was having blackouts, but I was very, very promiscuous. You know, I wanted the love, and looking back at it, I was desperate for it. So, if it meant for that little short amount of time that someone liked me enough to want to be with me, then that was good enough.

Derek, Madison, and Teresa all spoke about their experiences with intergenerational alcoholism and how this shaped their views and behaviour with drugs and alcohol. Derek and Teresa also discussed the physical and emotional abuse that they experienced growing up and how they both turned to drugs and alcohol to numb the pain.

### **Theme 3: Healing the Wounds: Sources of Strength, Success, and Helping Others**

The final theme that was found among all four participants’ accounts related to their sources of strength, what helped them become successful, and passing on this positivity to others. Teresa shared, “I have gone through a lot of things in my life and my whole existence, my calling in life, is to help others.” In reflecting on their school experiences that have influenced their lives, the participants provided examples and rich descriptions about how they were able to overcome hardships, gain strength, and experience success in their lives. Madison spoke about how asking for help and working with the resource teacher at school and with her mom at home helped her achieve success in high school:

I spoke up and said “Hey, I need help.”... I would also go do work with the resource teacher ... and I got caught up in everything.... My mom also helped me be successful in school ... She would say, “Why be shy? There is no point to that.” She would always tell me that if I needed help to just ask. She also helped me a lot with my homework. She never graduated high school, but she knew everything.

Brandon explained how his teachers going to a conference to learn more about FASD, and his educational assistant suggesting he attend youth group activities, have helped him within and beyond school: "So now they [his teachers] know what I have and how to help me better. I also go to a youth group and we play games and take camping trips." Teresa described how taking drama as an elective course in Grade 11 was a source of strength in school and in her life:

Looking back I've realized that drama saved my life. I got up on the stage, and all of a sudden I could be whoever I wanted to be, I could laugh, I could flip out.... It opened me up ... I became a different person. All of a sudden I had friends and I wasn't scared, you know, I wasn't hiding anymore, I didn't feel like a loser. It was like, I am who I am, and I can choose to look happy on the outside and could hide the sadness and pain that was inside.

Derek discussed how frequenting a youth community support centre and having the support of elders helped him overcome the lure of drugs and alcohol:

If it wasn't for the centre being there in my early upbringing, I don't think I would be here today ... And the elders in my life that were also there for me and said you can do it, you can do it, you don't need drugs and alcohol.

Another commonality among participants was a desire to help others. Teresa explained how she continues to stay clean and sober and how she uses her story to help and strengthen others who are in the same place she was:

I am here because everything happens for a reason. I am here not to overdose, not to get raped and killed, not to be on the street. No! That is not the reason that I have gone through all of this pain! I am here to survive all of this and to turn it around to help other people. That is what every single moment of my life is about. To grow me, to strengthen me, and in turn, to strengthen others.

Derek explained why he wanted to share his story of having been diagnosed with FAE with others: "If somebody else could use the information that I provide to help others like me, then I would like to share my experiences and get them out there ... People want to get information about fetal alcohol disorder. It's a misunderstood disorder." Both Teresa and Madison explained how they have gained strength and insight about themselves through the experience of being diagnosed. Here Teresa discussed how she came to forgive her birth mother for drinking while she was pregnant with her, and the clarity, strength, and purpose this brought to her life:

When I think of my mom drinking with me I get so angry at her. How could she do this to me? It hurt me for a long time, and I held a lot of anger inside for a really long time. But one day I came to realize that I just had to forgive her to move on with my life. And I think that one of my greatest accomplishments in life was being able to forgive her for doing this to me. This helped me realize that I do have a purpose in this world, I refuse to be labelled by anything because I know that I am capable of anything I put my mind to. I might have some definite struggles, but really who doesn't? I have survived against a lot of odds, and here I am, I will make a difference!

Despite all the struggles that the participants have confronted, they each found sources of strength and experienced success in their lives. For Madison, it was her mother

who provided her with the courage to speak out and ask for the help that she needed. Once she was able to ask for help, her teachers were more than willing to provide it for her, and she was able to experience success in school and graduated. For Brandon, it was his youth group and the responsibility that his teachers undertook to learn more about his diagnosis that helped him. In Teresa's case, it was drama class that provided her with the opportunity to freely express herself without fear of being harassed or teased. Investing in drama class allowed her to form friendships and provided a release from some of the pain from her childhood. Teresa also used speaking at an addictions centre to fulfill her calling to help others who are going through similar situations. Finally, Derek credited a local youth support organization and the elders in his life with his sobriety and success.

Derek's, Madison's, Teresa's, and Brandon's stories of living with a FASD reveal some of the hardships and successes they have experienced along the way. Despite the hardships these participants have faced, they have each found sources of strength and success that have made them resilient in the face of adversity.

## **Discussion**

The findings from the current study apply to FASD literature that explores individuals' educational experiences, how these experiences influenced their lives, and the sources of strength that have enabled these individuals to experience success and resiliency.

### **School Experiences Influencing Participants' Lives**

The first research question sought to understand the school experiences of participants who had been diagnosed with FASD and how these experiences have influenced their lives. Although the participants came from different ethnic backgrounds (Indigenous and non-Indigenous) and were raised in varying environments (e.g., parents who were abusive vs. non abusive, parents who were misusing vs. not misusing alcohol and/or drugs), the challenges they faced in both school and life were similar. The purpose of this study was not to understand participants' experiences through the filter of ethnicity, but instead to understand the common educational experiences of adults with FASDs and how these experiences influenced their lives. Two of the three main themes identified in the stories of the participants related to this research question: (a) school-related difficulties, and (b) abuse, addiction, and promiscuity or prostitution. Prenatal alcohol exposure clearly causes brain damage and is therefore associated with a host of learning, behavioural, and academic problems (Green, 2007; Saskatchewan Learning, 2004), such as: immature social and reasoning skills, difficulty generalizing information from one situation to another, memory difficulties, impulsive and hyperactive behaviour, distractibility, difficulty processing sensory information, poor fine and gross motor skills, difficulty understanding the consequences of actions, and the display of poor planning and listening skills (Government of Canada, 2007; Green, 2007; Saskatchewan Learning, 2004). These numerous cognitive, behavioural, and adaptive skill difficulties, which are common in those diagnosed with FASDs, may be the reason the participants in the current study experienced difficulty understanding school subjects.

In the current study, three participants spoke about having difficulty understanding school subjects, especially mathematics. Difficulties grasping the concepts presented in school understandably lead participants to become frustrated. Teresa recalled her frustration with math and exclaimed, “I wanted to get it and I wanted to learn.” The characteristics, strengths, and difficulties individuals diagnosed with FASDs demonstrate are individual and unique. Her comment reveals that educators must consider individual strengths and needs when teaching students with FASDs. Various evidence-based strategies can be used to improve the learning outcomes for students with FASD, such as presenting learning tasks in small steps, breaking down tasks using visual and tactile cues, and creating a nurturing learning environment in which visual distractions are minimized (Carpenter, 2011; Roberts, 2015). One area educators may need to supplement for students with prenatal alcohol exposure is the teaching of mathematical concepts, an area that seemed to be a major concern to participants in this study. When Duquette and Stodel (2005) interviewed 11 parents and 7 children diagnosed with FASD and asked them about their school experiences, parents indicated that all of the children who were still in school experienced difficulties in math. A second area educators may need to consider is the unique learning styles of individuals with FASDs. Teresa’s comment also reveals that students with FASDs may want to learn but do not always have the tools to do so. Therefore, instead of labelling these students as lazy or slow, educators need to try to teach them in different ways so they can understand, learn, and achieve success both inside and outside of school.

Participants in the current study also noted that behavioural and/or emotional problems such as fighting, hyperactivity, and gregariousness often got them into trouble at school. As Derek explained, “I was hyperactive ... so I was sent outside to the hallway a lot ... Being out in the hallway was also not good for me. I felt like an outcast.” Duquette and Stodel (2005) also noted that five of the seven participants in their study exhibited disruptive and aggressive behaviour problems or experienced emotional difficulties in school. Individuals with prenatal alcohol exposure present with a variety of behavioural issues including hyperactivity, aggression, inappropriate sexual behaviour, delinquency, and self-injurious behaviours (Green, 2007). This information is congruent with the current study’s findings, since two participants reported being hyperactive or disruptive in the classroom, one also reported aggressive behaviours such as fighting, and others discussed illicit drug use and promiscuity. Due to the common occurrence of these behaviours, educators must be aware that students with FASDs often display behaviours that can be potentially disruptive to the classroom setting. They must be prepared to deal with these disruptive behaviours from all students, not just those with FASDs, and find the most effective way to manage disruptions within their classrooms.

These behavioural and/or emotional concerns can also lead individuals with FASDs to experience difficulties performing adaptive behaviours and displaying appropriate social skills. For example, studies suggest that individuals prenatally exposed to alcohol are at a high risk for developing problem behaviours that often interfere with their participation in the home, at school, and in social environments (Riley & McGee, 2005). Since individuals prenatally exposed to alcohol have already been found to have poorer social skills than those who are not prenatally exposed to alcohol (Thomas et al., 1998), if disruptive behaviours are also present, this will further delay their social and adaptive



skill development. All participants in the current study revealed difficulty forming and maintaining friendships, discussed how they often felt as though they did not fit in, and were often bullied at school. As Teresa stated, “I never felt like I really fit in because it was hard for me to relate to other people.” Thus, the current study adds further support to what is already known about individuals prenatally exposed to alcohol having difficulty developing social and adaptive skills.

These common behavioural and/or emotional issues suggest the need for preventative interventions and counselling services for this population. Programs aimed at modelling appropriate emotional reactions, social skills, safety, and sexual health-related issues should be provided for individuals with FASDs and may need to be modified to accommodate for their cognitive differences. Another reason that the participants in the current study may have had so many negative educational experiences could be educators’ lack of knowledge about how to best support students with FASDs (Roberts, 2015; Ryan & Ferguson, 2006). Within the educational system, systematic research on the needs of students with FASD, or on the most effective educational strategies to use with these individuals, is needed (Ryan & Ferguson, 2006).

The participants in the current study spoke at length about their experiences with promiscuity and prostitution, alcohol and drug abuse, and physical and emotional abuse. These dangerous behaviours and harmful experiences seem to be all too common for individuals with FASDs (e.g., Massey, 1997; Rutman, 2013). Massey (1997) used hermeneutic phenomenology to explore the experiences of five women between the ages of 18 and 30 who had been diagnosed with FAS or FAE. Themes related to poverty, unemployment, prostitution, alcohol and substance use, sexual abuse, physical health, pregnancy, suicide, isolation, and inequality arose from the women’s stories (Massey, 1997). Thus, the women in Massey’s study shared many similar and painful experiences with the participants in the current study. As Teresa discussed, she was abused by her adoptive mother and expressed that she “hated Fridays, hated them, and I loved Mondays. Which is usually the opposite for most kids, but this is how I escaped my home.” This comment suggests that educators must be aware when there is a pattern like this occurring in one of their students. If a child is regularly worried about leaving school on Fridays or at the end of most school days, concerns should be raised and questions must be asked.

Individuals with FASDs are often placed in foster care or put up for adoption because birth parents are unable to care for their children (Jones, 2004; Rutman, 2013). However, it is common for children with FASDs to be living with one or both parents who have addiction issues (e.g., Astley, Bailey, Talbot, & Clarren, 2000). Those who work with individuals who have FASDs should be aware that their students could be dealing with a lot of issues at home. If signs of alcohol or drug abuse are suspected, the appropriate authorities must be notified. In the case of Madison and Derek, their birth mothers or parents decided to raise them while they were still battling their addiction to alcohol. As Madison explained in her interview, her mother quit drinking for her children, but not before her children were taken away from her and put into foster care. Once her mother was able to prove she was clean and sober, she was able to have her children back. Her mother then helped Madison learn to advocate for herself. Whereas Derek had no family stability and had to rely on community supports, specifically he frequented a youth community support centre and had the support of elders. Derek was

able to move past the abuse and addiction problems he experienced growing up with his biological parents and to graduate high school, gain sobriety, and become a hockey coach. Even though Derek and Madison did not have consistent family supports or stable home lives throughout their upbringing, they demonstrated resilience by persevering and experiencing success in spite of the hardships and challenges they experienced while being brought up by their biological parents.

### **Overcoming Challenges and Achieving Success**

Further examples of resilience among the participants were found in relation to the second research question, which explored the factors participants felt allowed them to overcome challenges in their life and achieve success. One of the three main themes identified in the stories of the participants, finding sources of strength in order to achieve success and help others, related to this research question. There are a number of protective factors that promote resiliency among individuals with FASDs, such as living in a stable home environment and having nurturing and supportive caregivers (Streissguth, Barr, Kogan, & Bookstein, 1997). Although the participants in the current study faced a multitude of adverse situations, they all persevered and demonstrated considerable resiliency and success in both the school system and life in general. Some of the experiences participants identified as allowing them to experience success and increase their resiliency included: help from knowledgeable and caring teachers, supportive caregivers or adults, and attending youth groups or centres within the community. These experiences were also reflected in the stories of the parents and individuals who participated in Duquette and Stodel's (2005) study. They found four factors that contributed to a successful school experience for individuals with FASD, three of which were similar to the experiences of the participants in the current study: appropriate programs and services, such as availability of educational assistants and specific accommodations for course work; caring teachers; and support from parents (Duquette & Stodel, 2005). All of the participants in the current study spoke about having a teacher's aide or attending the resource room in their school for extra help with assignments. Most participants felt this extra help allowed them to get caught up in their work and to experience success in school. Thus, the essential help educational assistants and resource room teachers provide should not be overlooked and should be made available to all students with FASDs. In addition, it is important for teachers to understand the characteristics of the syndrome and make appropriate accommodations for affected students (Carpenter, 2011; Roberts, 2015). Although the participants in the current study did not articulate this importance as fluently, they recognized the significance of having knowledgeable and caring teachers as vital components to their success. Brandon revealed how the teachers at his school took the time to attend a conference on FASDs so they could learn more about his disorder and understand how to best help him.

Another experience that helped the participants in the current study achieve success was the help of supportive parents and community members. In this case, parental support was viewed as giving advice and coaching the participants through certain situations in life. Madison revealed that her mother taught her everything she knew, which included how to become an advocate for herself at school. She attributed her

educational success to her mother and her powerful words of encouragement. Similarly, Duquette et al. (2006) found that parental support and advocacy contributed to persistence in high school and experiencing success in school among students with FASDs. Derek also revealed how the advice and wisdom from certain elders within his community had allowed him to gain sobriety and become successful in his life. Clinical observations have revealed that caregivers and families are the primary advocates for individuals with FASDs throughout their lifetime (Olson, Oti, Gelo, & Beck, 2009). Therefore, in order to increase the likelihood that individuals with FASDs experience resilience despite significant adversity, it is vital that high quality care giving and supportive and stable home environments are the focus for interventions. Caregivers who are clean, sober, and have the ability to advocate on the behalf of individuals with FASDs, will have the strongest positive impact on these individuals.

The participants in this study had resilient attitudes that were powerful, bold, and often selfless. Teresa revealed she believes she is here today “to survive all of this and to turn it around to help other people. That is what every single moment of my life is about. To grow me, to strengthen me, and in turn to strengthen others.” Neenan (2009) stated that many factors affect the development of resilience; however, the most important one is the attitude individuals adopt to deal with adversity. He suggested that attitude is at the heart of resilience. The resilient attitude Teresa was able to cultivate seems to have helped her to overcome her addiction to drugs and alcohol, deal with the pain from years of repeated abuse, and support her entrance into a post-secondary program to become an addictions counsellor. She refused to be labelled by her diagnosis and has shown she is capable of anything she puts her mind to. Madison also revealed a similar resilient attitude when she stated that although she is not ashamed of her diagnosis, it does not define who she is as a person. She powerfully stated, “I am more than partial FAS.”

A final experience that contributed to the resilience of the participants within the current study was their involvement in school activities and/or attendance at youth programs and community centres. This finding, which is supported by previous research considering interventions that have been used to successfully support individuals diagnosed with FASD (e.g., Astley, 2014; Jirikowic et al., 2010), suggests that individuals with FASDs should be encouraged to find an activity they enjoy doing and can do well. This could include something that is offered inside the school environment like participating in a drama class or playing sports, or an activity outside of school like joining a youth group and engaging in activities like camping trips. Whatever the activity is, the individual should be encouraged to keep honing his or her abilities and praised for his or her successes. Both Brandon and Derek explained how their involvement with youth programs and centres allowed them to make friends. These positive experiences reveal that these programs and centres may allow youth the opportunity to form friendships with peers with similar interests. Youth with FASDs often experience difficulty with social skills, and these programs offer additional opportunities for attendants to develop these vital skills. These centres also differ from the educational environment and thus allow attendants to express themselves in other often more creative ways, which may also contribute to friendship formation.

## Summary

The findings from this study demonstrated that it is important for family members, educators, and helping professionals, such as counsellors, psychologists, and speech-language pathologists, to have an understanding of FASDs and how prenatal alcohol exposure affects academic, behavioural, and social functioning. Professionals must also be aware of the living situations to which many students with FASDs are exposed, such as the history of substance abuse that is sometimes present. This awareness will help in identifying areas of student and family need and in establishing immediate and appropriate interventions when necessary, such as reporting instances of abuse or child endangerment to ensure immediate action by police and social service agencies, and ensuring child and family counselling is provided to support the development and maintenance of healthy adult-child relationships. Students with FASDs also require appropriate educational interventions and the support of caregivers, teachers, and helping professionals if they are to achieve success in the educational environment. That is, family members and school or community professionals need to ensure they are working to identify and meet the individual social, emotional, and learning needs of students with FASD (e.g., educators differentiating instruction). Another finding from the study was that family members, educators, and helping professionals need to encourage individuals with FASD to find and engage in activities they enjoy and can do well (e.g., participating in organized sports, becoming involved with youth programs and community centres) to develop social skills and meaningful relationships, facilitate the positive development of their self-esteem, and promote feelings of success, which in turn can help foster a resilient attitude. This resilient attitude is beneficial in allowing the person to feel more capable and may improve feelings of self-worth.

## Limitations and Future Research Directions

One potential limitation in this study relates to the respondents' self-reported experiences. This study focused on the educational and life experiences of adults with FASDs; therefore, the findings are based on the sole perspectives of the individuals who were interviewed. Others who may be asked the same information about each of these individuals (e.g., parents, teachers, siblings) may not see things in the same light as the individual. Often this is addressed in studies by interviewing the participants' parents, teachers, or siblings. However, the focus of this study was on highlighting the voices of individuals with FASD. Therefore, a second interview was requested where the participants could add any new information that they may have left out from the first interview and check that the information received was as accurate and comprehensive as possible. The student researcher worked to ensure that all participants understood what was being asked of them, that they were able to share their stories, and that their interests were protected.

When considering this study's findings and its implications for families, educators, and helping professionals, suggested future research topics could include further consideration of the experiences of individuals with FASD across the life span related to: (a) finding and engaging in activities they enjoy and can do well at school or in the community, and how these activities have helped or hindered their ability to develop their

social skills and foster meaningful relationships with others; (b) identifying and further exploring the protective factors individuals with FASD report as having helped them to support their development and meet any challenges they have encountered; and (c) considering whether any other individuals who report limited protective factors (i.e., brought up with little family stability) are still demonstrating resilience and/or leading healthy, productive lives. Enhancing our understanding of the experiences of individuals with FASD from their own perspective can only improve our ability to better support these individuals to experience success in their lives.

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## Appendix A

### Telephone Script for Participation Criteria

1. Thank you for your interest in the research project. Now I just want to make sure that you are able to participate in the study. So first of all, are you between the ages of 18 and 21?
2. Are you diagnosed with FAS, partial FAS, or ARND?
3. What was the process you went through to become diagnosed?
4. Are you willing to share your school experiences of being diagnosed with a FASD?
5. Are you in any sort of immediate crisis? (experiencing anxiety, depression, loss, break-up?)
6. Have you attended high school?
7. Great, now that we have covered that, I would like to set up a time to meet and hear about your school experiences. I have a room in the ... library at the ... campus that we could book; do you require directions and/or bus tickets in order to meet? Or if it works better for you, we could meet at one of the public libraries.

Great, thank you for your interest in the study, and I will call you back if you are chosen for an interview.



## **Appendix B**

### **Questions for First Interview**

1. What made you respond to the poster?
2. Describe what elementary and high school was like for you? Did you like it?
3. What did a good day look like for you in school?
4. What did a bad day look like for you in school?
5. Would you say school was a positive or negative experience overall?
6. Why? What made you feel this way?
7. How was it making friends in school?
8. What made it so?
9. How did you find getting along with different teachers?
10. When were you diagnosed with (FAS, partial FAS, or ARND)?
11. How did you react when you found out about your diagnosis? (angry, relieved, shocked)
12. How did your parents or guardians react to your diagnosis?
13. Did your life change in any way after you were diagnosed or learned about your diagnosis?
14. Did things at school change?
15. Did your thoughts about yourself change after you were diagnosed or you learned about your diagnosis?
16. What has your experience of being diagnosed with (FAS, partial FAS, or ARND) in school been like?
17. Did being diagnosed affect you positively or negatively in school?
18. What are some things that have helped you be successful in high school?
19. What things have not helped?

### **Questions for Second Interview**

1. After looking over the shortened version of the interview and your quotations, is there anything you have thought of that you would like to add, change, or delete?
2. Have you had any new thoughts or ideas since our last interview?